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# WHAT SUPPORTS EFFECTIVE CARE HOME RESEARCH ? : RECOMMENDATIONS FROM THE DACHA STUDY.

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Claire Goodman on behalf of the DACHA team

Centre for Research in Public health and Community Care - University of Hertfordshire



DATA

# DACHA Aims

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To establish what data needs to be in place to support research, service development and uptake of innovation in care homes.

To synthesise existing evidence and data sources **with** care home generated resident data to deliver an agreed data set - **(Minimum Data Set)** - usable and authoritative for different user groups.



# Outcome measures from international older adult care home intervention research: a scoping review

Sarah Kelly , Andy Cowan , Gizdem Akdur , Lisa Irvine , Guy Peryer , Silje Welsh , Stacey Rand , Iain A Lang , Ann-Marie Towers , Karen Spilsbury ... Show more

Age and Ageing, Volume 52, Issue 5, May 2023, afad069, <https://doi.org/10.1093/ageing/afad069>  
Published: 16 May 2023 Article history

# Contextual factors influencing complex intervention research processes in care homes: a systematic review and framework synthesis

Guy Peryer , Sarah Kelly , Jessica Blake , Jennifer K Burton , Lisa Irvine , Andy Gizdem Akdur , Anne Killett , Sarah L Brand , Massifufulay Kpehe Musa ... Show n

Age and Ageing, Volume 51, Issue 3, March 2022, afac014, <https://doi.org/10.1093/ageing/afac014>

## Data Collection in Care Homes for Older Adults: A National Survey in England

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### ABSTRACT

**Context:** In many countries, there is a specification for information that should be collected by care homes. So-called 'minimum data-sets' (MDS) are often lengthy, and report on resident health and wellbeing, staff, and facilities. In the UK, the absence of any easily accessible data on the care home population was highlighted at the start of the COVID-19 pandemic. Care homes faced multiple requests for data from external agencies who had little knowledge of what care homes were already collecting.

**Objective:** This study aimed to identify the range (and method) of data collected by care home organisations, in a country without a mandated MDS.

**Methods:** Online survey of care homes (with/without nursing) in England. Care homes recruited via research and care home networks, social media. Questions covered data content, storage, and views on data sharing, analysed with descriptive statistics.

**Findings:** 273 responses were received, representing over 5,000 care homes. Care homes reported extensive data on the health, care and support needs of individual residents, their preferences, and activities. Clinical measures and tools adopted from health were commonly used, but few collected information on quality of life. Care homes reported uses of these data that included monitoring care quality, medication use, staff training needs, budgeting, and marketing. Concerns over privacy and data protection regulations are potential barriers to data sharing.

**Implications:** These findings challenge the notion that incentives or mandates are required to stimulate data collection in care homes. Care home organisations are collecting an extensive range of resident-level information for their own uses. Countries considering introducing social care records or an MDS could start by working with care home organisations to review existing data collection and evaluate the implications of collecting and sharing data. A critical approach to the appropriateness of

### RESEARCH



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### KEYWORDS:

aged nursing homes; data collection; minimum datasets

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### METHODOLOGY

## Activity provider-facilitated patient and public involvement with care home residents

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### Abstract

**Background** In care home research, residents are rarely included in patient and public involvement and engagement (PPIE) despite their lived experiences of day-to-day care. This paper reports on a novel approach to PPIE, developed in response to Covid-19, and utilised in a large UK-based study focused on care homes. PPIE sessions were facilitated on behalf of the research team by Activity Providers (APs) already working within the care homes. This paper provides an account of how PPIE with care home residents can be achieved.

**Methods** An exploratory design was used to see if it was possible to support "in-house" PPIE, with researchers working at a distance in partnership with care home staff. The National Activity Providers Association recruited five APs working in care homes. A series of optional discussion or activity sessions were developed by the research team in partnership with APs, tailored to reflect the research topics of interest and to make sessions accessible to residents with differing needs.

**Results** APs facilitated four rounds of PPIE with up to 56 residents per topic, including individuals living with cognitive and communication impairments. Topics discussed included residents' views on data use, measuring quality of life and the prioritisation of care-related data for study collection. Feedback from the residents was observed to have unexpected and positive changes to participating care homes' practice. APs valued participation and working with researchers. They identified acquisition of new skills and insights into residents' thoughts and preferences as direct benefits. Challenges included time pressures on APs and managing emotive feedback. APs were able to approach residents at times convenient to them and in ways that best suited their individual needs. PPIE with residents provided different perspectives, particularly with respect to the importance of different types of data, and constructive challenge about some of the research team's assumptions.

**Conclusions** PPIE with APs as research partners is a promising approach to working in an inclusive and participatory way with care home residents. The voices of older care home residents, including those living with cognitive or communicative impairments, are important for the successful and meaningful completion of research.

**Keywords** Patient and public involvement and engagement (PPIE), Aged, Care home, Activity provider, Older people, Participatory action research

### ORIGINAL ARTICLE

## Public Involvement to Enhance Care Home Research; Collaboration on a Minimum Data Set for Care Homes

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**Keywords:** care homes | minimum data set | older people | public involvement

### ABSTRACT

**Introduction:** Information on care home residents in England is captured in numerous data sets (care home records, General Practitioner records, community nursing, etc.) but little of this information is currently analysed in a way that is useful for care providers, current or future residents and families or that realises the potential of data to enhance care provision. The DACHA study aimed to develop and test a minimum data set (MDS) which would bring together data that is useful to support and improve care and facilitate research. It is that utility that underscores the importance of meaningful public involvement (PI) with the range of groups of people affected. This paper analyses the involvement of family members of care home residents and care home staff through a PI Panel.

**Objectives:** The objective for the PI activities was to consistently bring the knowledge and perspectives of family members and care home staff to influence the ongoing design and conduct of the DACHA study.

**Methods:** The bespoke methods of PI included a dedicated PI team and a PI Panel of public contributors. Meetings were recorded and minutes posted. Feedback sessions were facilitated and participants on the PI recorded. A summary of the data collected

## International Journal of Population Data Science

Journal Website: [www.ijpds.org](http://www.ijpds.org)

## Data resource profile: the virtual international care homes trials archive (VICHTA)

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### Abstract

#### Introduction

Randomised controlled trials (RCTs) conducted in care home settings address a range of health conditions impacting older people, but often include a common core of data about residents and the care home environment. These data can be used to inform service provision, but accessing these data can be challenging.

#### Methods

The Virtual International Care Home Trials Archive (VICHTA) collates care home RCTs conducted since 2010, with >=100 participants, across multiple conditions, with documented eligibility criteria, initially identified from a scoping review. A Steering Committee comprising contributing trialists oversees proposed uses of fully anonymised data. We characterised available demography and outcomes to inform potential analyses. Data are accessible via application to the Virtual Trials Archives, through a secure online analysis platform. Trial recruitment is ongoing and future expansion will include international studies.

#### Results

The first phase of VICHTA includes data from six UK RCTs, with individual participant data (IPD) on 5,674 residents across 308 care homes. IPD include age, sex, dementia status, length of stay, quality of life, clinical outcome measures, medications, resource use, and care home characteristics, such as funding, case mix, and occupancy. Follow-up ranges between four and sixteen months.

#### Conclusions

VICHTA collates and makes accessible data on a complex and under-represented research population for novel analyses, and to inform design of future studies. Planned expansion to international care

Research Involvement and Engagement

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### PRACTICE

## Health and social care research from the frontline: perspectives from care home staff

Marlene Kelly, Emily Allison, Kerry Micklewright

### Abstract

Marlene Kelly and Emily Allison reflect on their forays into the world of health and social care research from their 'expert-by-experience' perspective.

Marlene Kelly  
Auburn Mere Residential Care Home, Watford, UK  
Emily Allison



# Supporting research in and with care homes

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## TWO EVIDENCE REVIEWS

PERYER G, KELLY S, BLAKE J, BURTON JK, IRVINE L, COWAN A, AKDUR G, KILLETT A, BRAND SL, MUSA MK, MEYER J, GORDON AL, GOODMAN C. (2022) CONTEXTUAL FACTORS INFLUENCING COMPLEX INTERVENTION RESEARCH PROCESSES IN CARE HOMES: A SYSTEMATIC REVIEW AND FRAMEWORK SYNTHESIS, *AGE AND AGEING*, VOLUME 51, ISSUE 3

KELLY, S., COWAN, A., AKDUR, G., IRVINE, L., PERYER, G., WELSH, S., RAND, S., LANG, I. A., TOWERS, A.-M., SPILSBURY, K., KILLETT, A., GORDON, A. L., HANRATTY, B., JONES, L., MEYER, J., GOODMAN, C., & BURTON, J. K. (2023) OUTCOME MEASURES FROM INTERNATIONAL OLDER ADULT CARE HOME INTERVENTION RESEARCH: A SCOPING REVIEW, *AGE AND AGEING*, VOLUME 52, ISSUE 5.

# Ensuring trial interventions succeed

Many care home trials have neutral findings

Unclear if neutral findings due to intervention ineffectiveness OR a consequence of study implementation processes or insensitive measurement tools.

Systematic review : 33 (32 interventions) process evaluations




**Procedural drift:** studies lost momentum over time

**Participatory action and learning :** authentic engagement, staff delivering the intervention as a collective

## Key Considerations:

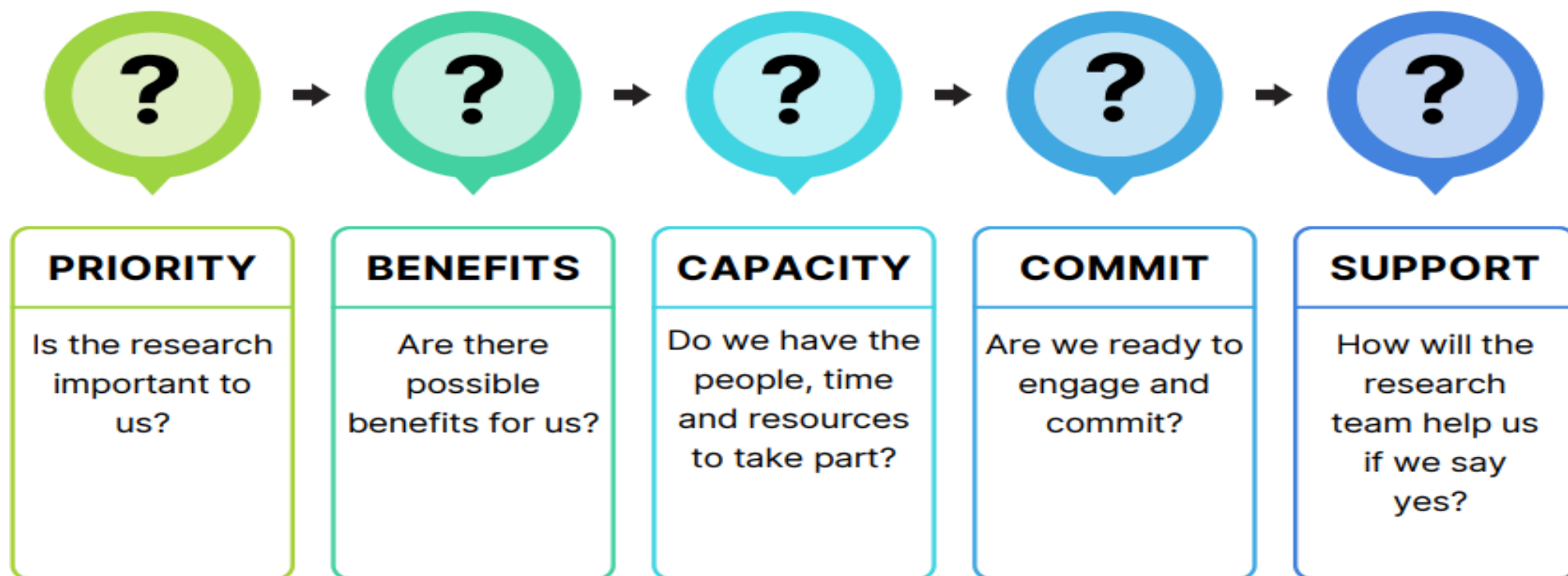
→ Read from left to right: to see what each team can think about individually and collaboratively from the design and planning phase, all the way to the intervention evaluation.

↓ Read from top to bottom: to see how each team can collaborate to tackle specific challenges.


	Context	Relationships	Training & Coaching	Communication		Sustainability	Flexibility & Adaptation	Evaluation
 <b>Research team</b> Designing the Protocol Engagement	Will the intervention fit with existing work routines in the care home?	Why does the care home want to participate? Is this interest shared across the whole organisation?	How can knowledge sharing activities include both learning and practice?	Establish a reliable and sustainable form of communication with the care home early on	Are materials provided to the care home easy to use, is the language used accessible to all?	What methods will help detect procedural drift from the study's aims and objectives?	Is there flexibility to allow for bespoke tailoring of the intervention?	Will effects of 'learning over time' be anticipated and accommodated in study analyses?
 <b>Collaborative team</b> Individual Context Positive Working Relationships	If new additions to staff work routines are added, what activities can be reduced or replaced in the same time period?	What will help the collaboration build rapport, air tensions, and resolve difficulties throughout the study?  How can the views and goals of the residents be included in the collaborative discussions?	How can ongoing learning and coaching be designed together to address identified needs?  How can knowledge sharing activities be accessible to all staff, including the management team?	When should collaborative meetings take place to discuss how the study is running, and how often should they occur? Are face to face meetings preferred?  What is the best method to keep in touch in between meetings to allow problems to be addressed early?		What methods of engagement will help sustain motivation and commitment?  How can positive experiences linked to the intervention be shared?	How will procedural drift from the study's aims and objectives be addressed to meet expectations of all stakeholders?	How can data collection be simplified for staff?  What are the effects of the intervention on the broader health and care system?
 <b>Care Home team</b> Internal Resources Team Dynamics	Can existing resources be reallocated whilst maintaining quality of care?	How will the intervention reach the residents who are likely to receive benefit?	How can any required training and coaching for staff take place during work hours?	Will sufficient time be allotted to discussing the study at regular staff meetings internally?	Is there sufficient capacity for staff to coordinate the study internally?	How will new or temporary members of staff be made aware of the study?	How will care home managers actively participate in overseeing intervention delivery?	Have adequate resources been allocated to optimise data collection?

# Are you ready to be involved in a research study?

## Guidance for care homes\*





 **PRIORITY**  
The study question matters for our care home

 **BENEFITS**  
The study may benefit our residents and/or staff



## CAPACITY

- We can commit the people, time and resources needed throughout the study
- A named staff member will coordinate research activities
- We can do study activities without compromising quality
- Our indemnity arrangements cover us

## COMMIT

- We will engage because we understand *how* the study might benefit us
- We have a plan for any training
- We can discuss the study regularly in home meetings
- We will make sure new and temporary staff are aware of study responsibilities



## SUPPORT

- We know how we will work, communicate with, and ask questions of the research team
- We know how any payments for taking part will happen
- We know how plans for knowledge sharing with staff, residents, families



**READY**



Intervention studies (436 papers, 396 datasets 2015-2021)

732 outcome measures **only 14** used more than 20 times

- Health measures dominated from hospital/clinical settings
- Typically measured functional status, mood and behaviour, and medications
- Fifth of research studies used information gathered routinely by the care home,
- **5 studies** Brief Pain inventory or Pain Assessment in Advanced Dementia.

# What would help?

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Care homes and researchers work together to **measure what matters** to older people and help to improve care home practice



Outcome measures that measure quality (e.g., quality of life or quality of care) suitable for research and **everyday practice** in care homes.



International agreement about the **best** outcome measures



Recognise that using different outcome measures to measure the same thing is **wasteful**



Need to know which outcome measures can show changes and trends **over time** in care home populations.



Case for **Core Outcome Sets** for clinical trials in long term care settings?

# Efficient use of data

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IRVINE, L., BURTON, J. K., ALI, M., BOOTH, J., DESBOROUGH, J., LOGAN, P., MONIZ-COOK, E., SURR, C., WRIGHT, D. AND GOODMAN, C. (2024) DATA RESOURCE PROFILE: THE VIRTUAL INTERNATIONAL CARE HOMES TRIALS ARCHIVE (VICTA), *INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE*, 8(6).

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# The Virtual International Care Home Trials Archive (VICHTA)

(6000+ older  
people, 340 care  
homes)

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Repurposing high Quality Anonymised Care Home trial data

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Pooled for secondary data analysis: a cost -effective way to improve care. e.g medications and symptoms/conditions

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> 6k residents with individual participant data with option to add more care home trial data

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Researchers can contribute data or request access to the data at the VICHTA website: [www.virtualtrialsarchives.org](http://www.virtualtrialsarchives.org)

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**First time** an archive has been developed based on a setting (care home) instead of a particular treatment or condition

# National Survey

273 responses  
representing 5k  
care homes

## Care home resident data routinely collected

**Aggregate data** (daily/monthly) external scrutiny (Care Quality Commission, Local Authority Contracting, Clinical Commissioning Groups, different NHS services, Health and Safety/environmental (duplication +++, minimal feedback)

**Individual** : residents' care needs e.g., preferences, medication, wound care, those at risk (e.g., falls, infection, choking), clinical measures, key events, visiting NHS staff input

## **Staff** and Staffing information

Hybrid systems for recording and storage (digital & paper) in different locations within care home

# Key findings

**Wide range of data already collected**

. [LSE Research Online+1](#)

**Use of clinical / health tools**

**(Need for critical assessment of tools being used)**

[Journal of Long-Term Care+1](#)

**Quality of life measures lacking**

[E Research Online+1](#)

**Multiple purposes for the data**

Homes use the data for monitoring care quality; managing medication; supporting staff training; budgeting; and for marketing. [LSE Research Online+1](#)

**Data storage & sharing challenges**

<b>Pain</b>	<b>245 (89.7%)</b>
Abbey Pain Scale	170 (62.3%)
Faces pain scale	41 (15%)
Pain map of body	67 (34.5%)
Pain Thermometer	10 (3.7%)
Brief Pain Inventory	7 (2.6%)
Pain Assessment in Advanced Dementia (PAINAD)	36 (13.2%)
Other measure of pain	19 (7%)



# Meaningful engagement

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KILLETT, A., MICKLEWRIGHT, K., CARROLL, R., AKDUR, G., ALLINSON, E., CRELLIN, L., DE CORTE, K., FOX, M., HANRATTY, B., IRVINE, L., JONES, L., KELLY, M., LLOYD, T., MEYER, J., SPILSBURY, K., TOWERS, M., TRACEY, F., WILLMOTT, J., & GOODMAN, C. (2025). PUBLIC INVOLVEMENT TO ENHANCE CARE HOME RESEARCH; COLLABORATION ON A MINIMUM DATA SET FOR CARE HOMES. *HEALTH EXPECTATIONS*, 28(1).

MICKLEWRIGHT K, KILLETT A, AKDUR G, BISWAS P, BLADES P, IRVINE L, JONES L, MEYER J, RAVENSCROFT N, WOODHEAD H & GOODMAN C (2024). ACTIVITY PROVIDER-FACILITATED PATIENT AND PUBLIC INVOLVEMENT WITH CARE HOME RESIDENTS. *RESEARCH INVOLVEMENT AND ENGAGEMENT*, 10(7).

# Public involvement

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Transparency about the extent, nature and influence of PI in care home research variable

**Panel** met 17 times family members and care home staff including junior staff

**National expert consultation group** consulted three times

**Public involvement team** w two senior researchers, Senior research assistant activity, sector representative and former carer

**Core Research team** meeting weekly joined monthly by PI team

**Study steering committee:** with two public representatives, six meetings



# Involvement of care home residents working with activity providers

## Care home residents often excluded from research engagement activities

### Multiple challenges

- Physical and mental health
- Confidence
- Power relations between residents, staff and family members
- Limited time and resources for researchers and flexibility

### Response

#### **Activity Providers** using different resources

Sessions with 208 resident contacts including people with cognitive loss

Residents talked about their feelings about how data should be used

Changed care home practices and challenged some researcher assumptions

Fostered a research culture with care home staff as partners



**Guidance** on resident assessment, outcome measurement and implementation



**New methods and resources** for research and engagement



**Prototype MDS 996**

residents from 45 care homes

2 software providers



3 Integrated Care Systems (ICS)

<https://dachastudy.com/>



FUNDED BY



DACHA team: Claire Goodman, Lisa Irvine, Gizdem Akdur, Maz Musa **University of Hertfordshire**, Sue Fortescue **Public Involvement** Sarah Kelly, Andy Cowan **University of Cambridge**, Guy Peryer, Anne Killett, Priti Biswas, Kerry Micklewright **University of East Anglia**, Barbara Hanratty, Vanessa Davey **Newcastle University**, Jenni Burton, **University of Glasgow**, Myzoon Ali **Glasgow Caledonian University**, Karen Spilsbury **University of Leeds**, Adam Gordon, Rachael Carroll **University of Nottingham**, Sarah Brand, Iain Lang, Jo Day **University of Exeter**, Ann-Marie Towers, Stacey Rand, Steve Allen, Nick Smith, **University of Kent**, Therese Lloyd, Arne Wolters, Liz Crellin, Kaat de Corte, Richard Brine **The Health Foundation**, Liz Jones, Julianne Meyer, **National Care Forum**, and **NIHR ARC East of England**.

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